



Cancer
Council

Understanding Palliative Care

A guide for people with cancer,
their families and friends

Treatment

Cancer Council Helpline

13 11 20

www.cancercouncil.com.au

Understanding Palliative Care

A guide for people with cancer, their families, carers and friends

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Note to reader

Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or health professional's advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

Cancer Council NSW

Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council's website at www.cancercouncil.com.au or phone 1300 780 113.



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Introduction

This booklet has been prepared to help you, your family and carers understand more about the benefits and practicalities of receiving palliative care.

Although palliative care is for people with any advanced, life-limiting illness, this booklet has been written specifically for people with cancer, their families, carers and friends.

The aim of palliative care is to enhance your quality of life and help you maintain your independence for as long as possible. To achieve this, a team of health professionals brings together their expertise from different fields of care. Working as a multidisciplinary team, they organise for you to have access to services that meet your physical, emotional, spiritual and practical needs.

The way palliative care is managed differs across Australia due to availability of services. It is also tailored to an individual's unique needs. It can be coordinated by your general practitioner (GP) or community nurse, or you may be referred to a palliative care physician and a specialist palliative health care team. Care may be provided in or out of your home. This booklet covers these issues.

Your GP or palliative care team will talk to you and your carers about your case. The question checklist and glossary of medical terms at the back of this booklet may help you in your discussions.

You can also call Cancer Council Helpline 13 11 20.

The information in this booklet was developed with help from medical experts, people using palliative care services, and Palliative Care NSW.

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When cancer is advanced

There are many types of cancer and they all develop differently. Some cancers grow slowly, some advance rapidly, and others are unpredictable in their behaviour. Some types respond well to treatment in most people, while other types are more difficult to treat successfully. Although many early-stage cancers can be treated, some people now living with cancer will die of the disease.

Advanced cancer is a term commonly used to describe:

- primary cancer that is unlikely to be cured
- secondary (metastatic) cancer that is unlikely to be cured.

Primary cancer refers to the first mass of tumour cells that have divided and multiplied uncontrollably in an organ or tissue. The tumour is confined to its original site, such as the bowel or lung.

Secondary cancer is when tumour cells from the primary cancer site break off and spread to other parts of the body by moving through the blood or lymphatic system. If cancer spreads, it is common for it to move into the liver, bones or brain. This spread is also known as metastasis.

Secondary cancer keeps the name of the original, primary cancer. For example, pancreatic cancer that has spread to the liver is still called pancreatic cancer, even though the person may have symptoms caused by cancer cells in the liver area.

Both primary and secondary tumours grow their own blood vessels in a process known as angiogenesis. This allows the cancer to get a direct supply of oxygen and other nutrients.

When cancer is advanced, different organs in the body can stop working properly. If the liver is involved, the levels of chemicals in the body can cause problems. Tumours can grow and press on vital organs, affecting the way the organs function and causing discomfort or pain.



Cancer Council Helpline can arrange telephone support in different languages for non-English speakers. You can also call the Telephone Interpreter Service (TIS) direct on **13 14 50**.

Even though medical interventions may not be able to cure the cancer, some palliative treatments may still be able to slow its growth or spread. Palliative medicine can also help manage pain or other symptoms associated with cancer and its spread. It can reduce side effects from cancer treatments. See page 12 for information about medical treatment used in palliative care.

As well as medical treatment, palliative care focuses on other emotional, practical and spiritual needs that people with advanced cancer and their families have, whatever stage the cancer is at. This approach helps to enhance people's quality of life.

For more information about advanced cancer, call Cancer Council Helpline 13 11 20 or visit www.cancercouncil.com.au.

“ There is still a life to be lived and pleasures to be found and disappointments to be had. Living with advanced cancer is a different life, not just a journey towards death. ”

Patient



Palliative care – key questions

Q: What is the aim of palliative care?

A: Palliative care allows people with advanced cancer to enhance their quality of life in a way that is meaningful to them. It supports families and carers in their adjustments to some of the lifestyle changes they also have to face.

The role of palliative care is:

- to help you achieve and maintain the best quality of life that you can for as long as possible
- to make sure your physical, practical, emotional and spiritual needs are catered for
- to help you feel in control of your situation
- not to prolong or shorten life, but to make the time you have available as valuable as can be for you and your family.

Palliative care incorporates a range of services offered by medical, nursing and allied health professionals, as well as volunteers and informal carers. This is called a multidisciplinary approach.

You will have regular appointments with your health carers so they can monitor and adjust your treatment and the care that you may require. This helps to prevent or resolve any problems that may arise because of the illness.

“ I’ve been having palliative treatment for five years. I’m not trying to get rid of the disease, just keeping it under control. My quality of life is excellent. ” *Patient*

Q: Does it mean end-of-life care?

A: Palliative care is not simply about dying. It's about living for as long as possible in the most satisfying way you can, within the limits of your illness. While some people may only use palliative care services for a few weeks or months, the number of people receiving palliative care for several years is increasing. Because improved treatments can help stop the spread of cancer and relieve side effects, cancer is considered a chronic illness for many people.

One reason that some people don't access palliative care services early – or at all – is because they are afraid that by doing so, it somehow means they have given up hope or are going to die soon. The reality is that some people do die from cancer. As people draw closer to death, then end-of-life care becomes an important aspect of palliative care.

Q: Does it prolong life unnecessarily?

A: The role of the palliative care team is to provide specialised multidisciplinary care. The team does not try to prolong life but tries to enhance people's quality of life and help them with any changes and end-of-life issues in their preferred place of care.

Q: Is it the same as euthanasia?

A: Palliative care and euthanasia are not the same thing. Palliative care is about coordinating medical and support services so that someone with a life-limiting illness is made as comfortable as possible. Palliative care can help a person maintain quality of life, but it does not aim to lengthen or shorten life. Euthanasia is when a person's life is deliberately ended so that they avoid suffering from an incurable condition or illness. It is illegal in every state and territory in Australia.

Q: How can palliative care help?

A: The palliative care team is there to help make life easier for you, your family and carers. Besides the specific medical and support services that palliative care offers, which are discussed later in this booklet, there are many general benefits.

- If you're at home, the team helps to keep you out of hospital by regularly checking on you, either by phone or a house visit.
- Your care is coordinated by one person, usually a community nurse or a palliative care nurse, who communicates with all members of the team on your behalf.
- Communication with the team may help reduce feelings of isolation or not being able to cope.
- Learning how to make adjustments around the house can reduce stress for both you and your family.
- Support given to your family helps them to be more effective in looking after you.
- The palliative care team can help you plan for your future needs (such as the type of care you may need or where you will receive the care).

Another aspect of palliative care is giving you and your family emotional support, particularly if you are close to dying. Your team can talk to you about any needs or desires that you may have, and can help you achieve your goals. Some people have specific

““ Take care of all your end-of-life jobs and then try to live life at the optimum level you are capable of. ””

Patient

end-of-life wishes; others seek to make the most out of each day. You might focus your energies on short-term plans, enjoying time with friends and family, and reflecting on the joys in your life.

As well as the general emotional support provided to you by the palliative care team, a social worker or counsellor can help you and your family deal with issues of loss and grief. Your family may be eligible for bereavement counselling, although this is not available in all areas. The palliative care team will be able to direct you or your family members and carers to bereavement information and resources.

Q: When can I access palliative care?

A: It's advisable to access palliative care as early as possible, even if it's just to make contact with the palliative care team. You can find out what the different team members do and which services might be relevant now or in the future. Being able to deal with problems earlier rather than later will help reduce stress on you and your family.

You can have palliative care for as long as you need: you may live comfortably for months or years; or your illness may advance rapidly so that your care is focused on end-of-life needs soon after your referral. Whatever stage you're at, your team will continually assess your changing needs and will adjust your care as required.



A report by the Department of Health and Ageing found that most people who were offered palliative care wished that they had been referred to it earlier than they had because of how much the services benefited them.

Q: Who will organise my care?

A: The way you receive palliative care depends on your situation:

- Your primary health care provider, such as a GP or a community nurse, may coordinate your palliative care.
- If your needs are complex and beyond the scope of care of your primary health care providers, you may be referred to a specialist palliative care team. If your condition improves, or you no longer need the assistance of the specialist team, your GP or community nurse can become involved again.

You generally need a referral to access the specialist palliative care team, so you should speak to your GP or community nurse.

Once you've been referred, the team will always consult your GP or nurse about your care and treatment. It is also important for your key family members or carers to participate in these discussions, as they often will be providing most of your ongoing, day-to-day care.



Finding hope

Sometimes people don't access palliative care services because they hope that a cure will be found for their illness. You may also find that your primary health care provider, such as your GP, is reluctant to talk about palliative care because they don't want you to think that they have given up hope.

However, you can still benefit from palliative care without giving up hope. People can have palliative care for several months or years and continue to enjoy many aspects of their life. You may take pleasure in various activities, such as doing

Q: Where do I receive palliative care?

A: You can have palliative care in different places depending on your situation, where you live and the support available to you. Care can be provided at home or in an aged care or residential care facility, palliative care units, hospitals, hostels or hospices. Patients can move between these settings if their needs change.

If you are cared for at home, you and your carers can be supported by community palliative care services. Alternatively, you may be admitted to a public hospital, hospice or other facility. You may be covered for care in a private hospital if you have private health insurance. Check with your health fund.

Many people prefer to receive palliative care at home, but they may feel that they will be too much of a burden on their family. An important role for the palliative care team is to assess the best place for your care. They will consider your home environment and your support networks before discussing the options with you, your family and carers.

small projects, talking to friends, or exploring new hobbies. You may find that a creative activity, such as writing or art, allows you to record your feelings and helps you to make sense of your changed situation.

As your illness progresses, you may hope to live as comfortably as you can for as long as possible.



Q: Will I lose my independence?

A: The palliative care team gives you choices to help you remain independent for as long as possible. An example is getting a ramp installed at home so you don't have to use the steps. The team respects your wishes if you don't want to take up their suggestions.

Q: Will I still have medical treatment?

A: Medical treatment for palliative patients is an important part of care. It aims to manage the physical and emotional symptoms of cancer without trying to cure the disease. Some examples of palliative medical treatment are:

- radiotherapy to reduce pain when cancer has spread to the bones
- chemotherapy to stop the cancer growing into other organs
- medication to relieve constipation, nausea or pain
- medication for depression, anxiety or insomnia.

Call Cancer Council Helpline 13 11 20 for more information on medical treatment for advanced cancer, and detailed information about cancer pain and pain medication, including opioids such as morphine.

Q: Will I be told my prognosis?

A: Some people want to know whether and when they will die from cancer; others don't wish to know. If you are offered palliative care, it does usually mean that the cancer is unlikely to be cured, and therefore, at some stage, you may die because of the cancer.

However, no-one can tell you exactly when you are going to die. Your doctors may be able to give a general indication of your life expectancy, but everyone is unique and responds differently to medical, social, spiritual and emotional care.

Dealing with death is difficult and confronting for most people and their families, whatever their cultural background or religious beliefs. Talking over any fears, worries, guilt or other emotions can help you come to terms with your condition. Consider sharing your thoughts with your loved ones or speak to a counsellor, psychologist or spiritual adviser. Cancer Council has information about coping with your emotions.

Q: Do I have to pay for palliative care?

A: The Commonwealth and State Governments fund core palliative care services so that they are free in the public health system whether you receive care at home or in a public setting. However, sometimes you may need to contribute to the costs of care. Some examples are:

- hiring specialised equipment for use at home
- paying for your own nursing staff if you elect to stay at home and require round-the-clock assistance
- paying for massage therapy used with physiotherapy services
- paying an excess if you have health insurance that covers palliative care and you go to a private hospital
- accessing respite services that may charge a small fee
- seeing a complementary therapist in private practice
- paying a dietitian's fee that is not covered by a Medicare rebate.



Cancer Council has practical information on health care rights for people with cancer. It covers topics such as specialist care, second opinions, privacy, finances, insurance and advanced cancer issues. Call the Helpline on **13 11 20** for a free copy.



Which health professionals will I see?

Your palliative care team will be made up of medical, nursing and allied health workers who offer a range of services to assist you, your family and carers throughout your illness, whether you are being cared for at home or in another setting.

Some roles overlap and assistance varies across Australia, but the most common health professionals are listed in this chapter. You won't necessarily see all these people – your GP, nurse or palliative care specialist will work with you to determine which services will benefit you the most.

General practitioner or family doctor:

- will continue to see you for day-to-day health care issues if you are being cared for at home
- will liaise with your nurse and/or palliative care specialist about the coordination of your ongoing care
- ideally can make home visits
- can refer you to a palliative care specialist or organise your admission to hospital or a hospice if your circumstances change
- can assist your family and carers with grief issues.

Nurse:

- coordinates other health professionals and works out what care you need, including home nursing or personal care assistance



If you are at home, you may receive care from a community nurse or a palliative care nurse.

- makes sure you have access to medicines and other treatments for pain and symptom relief, and talks to you about how to take your medication
- helps you with practical things, such as knowing what to expect and how to pace your day.

Palliative care specialist or physician:

- can prescribe or recommend treatment for pain, nausea, constipation, anxiety, depression or delirium, and any other symptoms you may have
- can visit you in your home, as well as in hospital, a residential care facility or hospice
- communicates with and advises the oncologist and your GP so your treatment is well coordinated
- can refer you and your family to a grief counsellor or a psychologist
- assists with decision-making about care choices.

Counsellor or psychologist:

- encourages you to talk about any fears, worries or conflicting emotions you may be feeling
- helps you to work through feelings of loss or grief
- can assist you and your partner with relationship issues
- helps you resolve problems so that you can find more pleasure in your life
- teaches you strategies to handle any anxiety you have
- may show you meditation or relaxation exercises to help ease physical and emotional pain
- can help you to communicate better with your family
- provides bereavement care to your family and carers.

Pastoral carer or spiritual adviser:

- supports you in talking about any spiritual matters on your mind
- reflects with you about your life and helps you search for its meaning, if appropriate
- helps you to feel hopeful and develop ways to enjoy your life despite your illness
- may organise special prayer services for you
- can bring you into contact with other members of your faith
- may discuss general emotional issues, as many are trained counsellors.

tips

- Ask your palliative care team if they have a 24-hour telephone service and keep the number by the phone for any unexpected problems.
- If you have certain cultural or religious beliefs about death and bereavement, or certain family customs, talk to your palliative care team early on to see if your customs can be integrated into your palliative care.

Social worker:

- provides counselling and gives you and your family emotional support
- discusses ways of coping and how to emotionally support your children
- may help you to work out who among your friends, family and neighbours you can ask to become your support team
- tells you about useful services such as home respite care, meal services, the mobility parking scheme, personal alarms, laundry services, and aged care services
- helps you access financial support you're entitled to.

Occupational therapist and physiotherapist:

- can help make the physical aspects of your daily activities easier, such as walking, showering, and getting into and out of bed and chairs safely
- can help organise equipment hire or modifications to your house for a safer, more accessible environment
- teach your carers and family the best ways to move you or help you sit and stand
- assist with pain relief techniques such as positioning your body appropriately, using hot and cold packs, and stimulating nerves
- advise you on physical aids to improve your mobility, such as a walking frame or a device to help you put on your socks
- show you how to exercise to reduce pain and stiffness, and to increase mobility and energy
- may also work with a massage therapist for relief of stiff and sore muscles or swelling.

Dietitian:

- works out the best eating plan for you
- helps you or your carer choose appropriate food and nutritional supplements
- tries to resolve any digestive upsets, such as poor appetite, nausea or constipation
- assesses and helps you manage any eating and swallowing problems
- supports your carer.



If your GP refers you to a dietitian in private practice as part of your Enhanced Primary Care (EPC) plan, you are eligible for a Medicare rebate.

To find out more about how dietitians can help you, see the Dietitians Association of Australia website, www.daa.asn.au.

Brian's story

Janine Sayers' husband received palliative care at home for seven months during his illness. The following story highlights how palliative care services can benefit someone with cancer, their family and carers. Availability of services does vary from area to area. Ask your GP or call **Cancer Council Helpline 13 11 20** to find out what you can access.

“ Brian was diagnosed with a brain tumour when he was 41. Until then, he had been extremely fit and healthy. We had five beautiful children and ran our own business. We had no idea that our lives were about to be forever altered.

Brian was operated on five days following diagnosis, and some weeks later began a course of radiation and chemotherapy. Not long after this, he required further surgery, allowing him some respite for a few months. But then the nurses suggested we call in the palliative care team.

My first reaction was, “But we don't need palliation.” I feared what this meant. But the nurses took the time to explain that it was much more than just nursing a dying person. It was about holistic support and understanding, ensuring that Brian could still 'live' as best he could in the time he had left.

When I asked my GP why doctors are so reluctant to suggest palliative care, he said some patients found it too difficult to deal with. Our feeling was that to know the truth about the diagnosis and what may lie ahead was essential.

Brian was able to enjoy the other services palliative care offered, whilst he was still well enough to appreciate it. He was able to join us at our daughter's debutante ball. A nurse helped bathe and dress Brian and escorted him to the reception centre. She returned later to collect him and stayed with him until I returned home. It will be a memory that will be with us forever. And the photos from that night, we treasure enormously.

Brian also enjoyed the massage therapy offered until his death. As a family, we appreciated the work of the social worker. She helped Brian and I talk about difficult and confronting issues. She helped the children understand what was happening. The respite care offered was also a welcome relief. I needed the respite to remain strong for Brian and our children.

Although palliative care is much more than nursing, I cannot discount the wonderful support these nurses offered us. These 'angels' visited, medicated and reassured. They gave me answers to questions that the doctors found too confronting to answer. The nurses gave Brian love and dignity to the end.

Now to his death. I have to be honest – I was fearful. We were all fearful of him dying at home. So a fortnight before Brian died, palliative care organised a bed in a local private hospital. But after a while, we worked out that home was indeed the best place for Brian. So we took him home, for the last time.

Palliative care gave us so much. The team gave Brian the nursing and the care he needed. They gave the rest of us the strength to see it through. They became a part of our family – they were like angels who would appear, see things right and then leave us to be a family again. My family would not have coped nearly as well without them. Palliative care is something not to be feared but embraced, if the need arises. ●●

Source: Adapted and reproduced with the permission of Palliative Care Australia from its publication entitled *A Journey Lived – a collection of personal stories from carers* (2005).



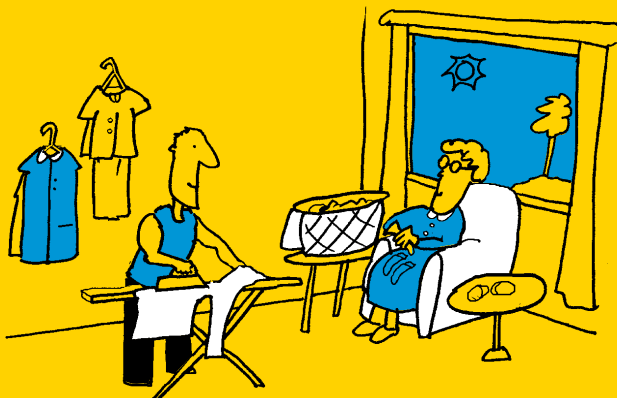
Volunteer help

Volunteers can be an important part of a palliative care team. They carry out a range of support activities, such as helping directly with your care, taking you shopping or to appointments, giving your carer a break, minding children, doing basic jobs around the house, or simply providing companionship and a non-judgmental presence.

Some specialist palliative care units include volunteers who may become part of your team. Usually volunteers only help out with specific, agreed tasks. Despite being unpaid, they are bound by the same professional standards as paid members of the team. They go through a thorough selection process that includes training and criminal history checks. If you think a volunteer would be of help, talk to your nurse who can refer you to the coordinator of volunteer services in your area.

You can also ask someone you know to volunteer to help you. Your social worker can help you prepare a list of people you would feel comfortable approaching.

You may feel embarrassed about asking for help, but you will probably find that many people want to do something for you. If someone offers to help, give them a particular task so that they don't have to guess what might be useful.





Other assistance

Useful organisations and resources

Commonwealth Respite and Carelink Centres – are a one-stop shop for accessing free, confidential, comprehensive information about services that can help with your care and assist you to live independently for as long as possible. Advisers can talk to you about equipment hire, nursing care, allied health services and programs such as Home and Community Care (HACC), which provides eligible people with short-term subsidised domestic help. Call 1800 052 222 or see www.commcarelink.health.gov.au.

Palliative Care Australia and its state member organisations – are key organisations that promote palliative care information and standards. They have many useful resources, such as fact sheets, a specialist palliative care services directory, and detailed information on living with a life-limiting illness. See www.palliativecare.org.au.

Cancer Connections – is an online discussion forum run by Cancer Council for people with cancer, their families, carers and friends to connect with others. You can read and write comments or blogs, ask questions or join a live chat. Log on at www.cancerconnections.com.au.



Pets Of Older Persons (POOPs) is an RSPCA program for people receiving palliative care who don't have friends or relatives who can help look after their pets. Visit www.rspca.org.au.

Financial support

For many people, an illness in the family can be a financial strain. This may be caused by extra out-of-pocket costs or from loss of income. For example, if you have to stay at home round-the-clock, household bills will rise and you and your family may eat more pre-packaged meals to save time and energy. You may need to pay for childcare, transport, medication and equipment. These extra costs can cause you and your family a lot of stress.

Ask your social worker about any financial or practical assistance available to you and your carer, and apply for it as soon as possible. You may be eligible for assistance from the government, volunteer bodies, church groups or your local council.

“ If I had one tip for other carers, it would be to find out about as many practical and financial services as possible, and apply for them early on. Then be realistic that you will have to pay for some things yourself, and be grateful if you are actually granted some assistance down the track. ”

Carer

Government assistance

Centrelink offers financial support for people with a long-term illness and for primary carers. For Disability, Sickness and Carer enquiries, ring Centrelink on 13 27 17 or visit the website at www.centrelink.gov.au. There are different benefits available:

- The Sickness Allowance is for people who are temporarily unable to work due to illness. The Disability Support Pension is for people who have not been able to work for two years or more. Both are income- and asset-tested.

- The Carer Payment is for carers who provide constant care in the home of the person you are caring for. This payment is income- and asset-tested.
- The Carer Allowance is for carers who provide a significant amount of assistance, either in their own home or in the home of the person with cancer. The allowance is not means tested; you may be eligible for it if you are working or receiving another type of pension.

Cancer Council Assistance Programs

Cancer Council runs various programs to help people with cancer who are facing financial challenges.

- A one-off payment is available to those in a financial crisis.
- Subsidised counselling can be arranged for people who wish to talk to a counsellor or psychologist but can't afford the full fee.
- Cancer Council may be able to organise free legal advice on issues such as will preparation, advance care directives and enduring powers of guardianship. Call the Helpline on 13 11 20 to see if you are eligible.

For further information about these programs, talk to your social worker or contact Cancer Council Helpline.

**These services may not be available in all state Cancer Councils.*



People with cancer or their carers may be able to access their superannuation early if they are facing severe financial hardship. People with a terminal illness can get the money as a tax-free lump sum. Call your superannuation fund to find out how to apply.

Complementary therapies

If you have been referred to palliative care services because your cancer is advanced, you may wonder whether there are any complementary or alternative therapies that you should try in case they offer some chance of a cure. The decision to use complementary or alternative therapies is yours to make, but there is no scientific evidence to prove that such therapies will provide a cure.

However, some complementary therapies may help you enhance your general well-being and cope better with pain and other symptoms you have, such as insomnia, anxiety or digestive problems. There are many types of therapies, including acupuncture, massage, aromatherapy, relaxation, herbal medicine and nutrition. While some cancer treatment centres offer therapies as part of their services, you may have to go to a private practitioner. Self-help CDs or DVDs can also guide you through different techniques.

Let your doctor know about any complementary therapies you want to use. This is important, as some therapies may not be appropriate, depending on your conventional treatment and state of health. For example, some herbs or nutritional supplements may interact with your medication, resulting in harmful side effects.

Call the Helpline for more information and resources about complementary therapies or alternative therapies.

“ I found it difficult to relax. Regular aromatherapy massage changed that. It also helped me to maintain mobility and it relieved discomfort and tightness. ”

Patient



Information for carers

Many people are fortunate to have a personal carer to help look after them. Usually a carer is a spouse or an adult child, but often other relatives, friends or neighbours will take on a significant caring role. Carers do not have to live with the person whom they support, but they provide care on a regular basis. Carers are a crucial – but often overlooked – part of the health system.

Caring can be a rewarding experience, but it can also be very draining and isolating, especially if you are caring for someone full-time. It is vital that as a carer you remember to take care of yourself too.

Accessing palliative care services for the person you are supporting is an important step in helping both of you. By accepting assistance, you will be able to share your workload, which will help you to cope better with the demands of caring.

If you are a primary carer, it is also important to participate in discussions with the palliative care team and the person you are caring for, as any decisions made will affect you too. If the person you are caring for wants their case history to remain confidential, explain that it will be helpful for you both if you are involved in any communication relating to their health care.

“ It was very hard work, but I found that caring for my mother at home was one of the best things I could have done for her in her greatest time of need. ”

Carer



Contact the Helpline for more information on Enduring guardianship and advance health care directives.

For more information about being a carer, call Cancer Council Helpline 13 11 20 to find out more about different resources or to request free resources for carers.

Respite care

Respite care is available to give you a break from your caring role. Respite can be given in your home, or the person you are looking after may be admitted to a respite care centre or, in some cases, a hospital or hospice.

Respite care can be for a couple of hours, overnight or for blocks of days. You can access respite care for any reason. For example, you may need time out to access health care for yourself; you may want to visit friends or other family members; or you just might want to catch up on some much needed sleep at home.

Some carers don't access the service because they feel guilty or concerned about leaving the person they are caring for. However, the service is there because caring can be a very difficult role and can challenge your own well-being. By allowing yourself a break, you will probably find that you can continue your caring role more effectively when respite care has finished.

The Department of Health and Ageing's Commonwealth Respite and Carelink Centres can provide emergency respite, as well as referring you to other organisations that provide respite services if you know you will need some assistance in advance.

It's best to make contact with a Commonwealth Respite and Carelink Centre early on, even if you don't have any immediate plans to access respite care. This will help the adviser to be aware of your situation when you do need respite, either planned or in a crisis.

You are eligible to access up to 63 days of residential respite care every calendar year. If you're receiving a Carer Allowance or Payment from Centrelink, you will continue to be paid for the days the person you are looking after is in residential care. Phone 1800 052 222 to discuss your situation.

Jackie's story

Jackie's mother Diana had advanced lung cancer and the family wanted her to be cared for at home. As her mother's primary carer, Jackie was supported by the local palliative care team.

A nurse coordinated Diana's discharge from hospital and organised for Jackie to hire a hospital bed and purchase other equipment, such as bed pans, for her mother. A physiotherapist from the hospital taught Jackie how to use the bed and equipment, and showed her ways to lift and move her mother safely. A palliative specialist prescribed medication and made sure Jackie knew how to administer it to Diana.

As Diana needed round-the-clock nursing care, Jackie paid for agency nurses to work on a 24-hour roster. The palliative care team visited every day and were available on the phone whenever Jackie had questions. After Diana died, surrounded by relatives and in familiar surroundings, Jackie received bereavement counselling through the hospital to help her come to terms with her mother's illness and death.

Counselling and mentoring

Carers often experience a range of conflicting emotions. If the person you are caring for is your partner, you may also be confronted with issues relating to sexuality and intimacy. Talking confidentially with a counsellor or social worker about these feelings may help you cope better, learn communication strategies, and come to terms with changes in your life.

You and your family may be eligible for grief and bereavement counselling provided through the palliative care team. Talk to the coordinating nurse or social worker for information.

The National Carer Counselling Program (NCCP) – provides short-term counselling for carers. This is available through Carers Australia, an association for relatives and friends who are carers. It provides fact sheets, support kits and telephone assistance to help carers access resources, find solutions to problems, and talk about their experiences. Carers Australia also runs support groups and has an online discussion board for carers under 25. Visit the website at www.carersaustralia.org.au or phone 1800 242 636.

Young Carers Respite and Information Services Program – helps people under 25 who have taken on a significant caring role. Administered through the Commonwealth Respite and Carelink Centres, it offers respite, help with school work and practical issues, and social activities. Visit www.youngcarers.net.au.

LifeCircle – supports carers of people who wish to die at home and provides ongoing mentoring to carers by phone, online or through outreach programs. For enquiries, phone 1800 132 229 or see www.lifecircle.org.au.



Children with advanced cancer

The majority of children and teenagers with cancer survive, but a small number do die. Palliative care for young people focuses on enhancing their quality of life by addressing physical, social, spiritual and emotional needs. Families are also supported through practical, social, spiritual and emotional care, which often continues following a child's death.

Elements of palliative care are often integrated early on with curative treatment, but sometimes symptom relief ends up becoming the key focus of care when the cancer cannot be controlled any longer.

The following organisations specifically support young people with cancer and their families by providing financial assistance, counselling, resources, respite care and palliative care. Your hospital social worker will also be able to provide support and may know of other useful networks in the community.

CanTeen – An organisation for young people aged 12 to 24 living with cancer. It provides resources for adolescents, including information on palliative care and end-of-life issues and an interactive online forum. It also runs activities such as camps and outings. See www.canteen.org.au or phone 1800 226 833.

Redkite – A charity that helps children and their families through cancer by providing emotional guidance, including bereavement support, financial assistance and educational services. For more information, talk to the social worker at the hospital, visit the website www.redkite.org.au, or phone 1800 334 771.

Kids with Cancer Foundation Australia – Provides financial assistance to families of children with cancer and helps fund projects in public hospitals and oncology units. To discuss your family's needs, phone 1800 255 522, or for more information, go to www.kidswithcancer.org.au.

Palliative Care Australia – Has a detailed resource called *Journeys*, which helps families and carers prepare for different situations they may face as they live with their child's illness. Visit the website www.palliativecare.org.au and click on 'Journeys' to access.



Seeking support

When you are referred to palliative care or while you are having palliative care, you may have a range of mixed emotions. Many people feel shocked, fearful, sad or angry. Others may feel relief or have a sense of inner peace. On some days they may feel hopeful, and on other days, they may feel anxious. Some people may also have ongoing depression. If this happens to you, it is important to tell your doctor, as medication or counselling can help.

You may find that while some people you know are supportive, others may not even know what to say to you. This can be difficult, and you may feel lonely or upset. If you need to leave work due to the illness, this may cause further sadness or stress.

It will probably help to talk about the different feelings you have. Your partner, family members and close friends can be a good source of support, or you might prefer to talk to:

- members of your treatment team
- a counsellor, social worker or psychologist
- your religious leader or spiritual adviser
- a support group – see next page
- Cancer Council Helpline 13 11 20.

If you have children, the idea of telling them about the cancer can be unsettling. Cancr Council has a range of free resources to help people deal with the emotions that cancer may bring up.



If your family or friends have questions you cannot answer, suggest they ring Cancer Council Helpline too.

Talk to someone who's been there

Getting in touch with other people who have had a similar experience to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone. There are many ways for you and your family members to connect with others for mutual support and to share information.

In these support settings, people often feel they can speak openly and share tips with others. You may find that you are comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears for the future.

Ask your nurse or social worker to tell you about support groups in your area. Cancer Council Helpline staff can also let you know about suitable support groups or peer support programs.



Cancer Council support services available for patients, carers and family members*

- **Face-to-face support groups** – often held in community centres or hospitals
- **Online discussion forums** – where people can connect with each other any time – see www.cancerconnections.com.au
- **Telephone support groups** – for certain situations or types of cancer, which trained counsellors facilitate
- **Peer support programs** – match you with a trained volunteer who has had a similar cancer experience, e.g. Cancer Connect.

** Not available in all areas*



Useful websites

The Internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

Australian

Your local Cancer Council

Australian Capital Territory	www.actcancer.org
New South Wales	www.cancercouncil.com.au
Northern Territory	www.cancercouncilnt.com.au
Queensland	www.cancerqld.org.au
South Australia	www.cancersa.org.au
Tasmania	www.cancertas.org.au
Victoria	www.cancervic.org.au
Western Australia	www.cancerwa.asn.au

National websites

Cancer Council Australia.....	www.cancer.org.au
Cancer Australia.....	http://canceraustralia.gov.au
Cancer Connections.....	www.cancerconnections.com.au
Carers Australia.....	www.carersaustralia.com.au
Department of Health and Ageing.....	www.health.gov.au
Commonwealth Respite and Carelink Centres.....	www.commcarelink.health.gov.au

Palliative care websites

ACT Palliative Care Society.....	www.pallcareact.org.au
Palliative Care Australia.....	www.palliativecare.org.au
Palliative Care NSW	www.palliativecarensw.org.au
Palliative Care Northern Territory.....	www.nt.palliativecare.org.au
Palliative Care Queensland	www.palliativecareqld.org.au

Palliative Care Council SA..... www.pallcare.asn.au
 Palliative Care Victoria..... www.pallcarevic.asn.au
 Palliative Care WA..... www.palliativecarewa.asn.au
 Tasmanian Association
 for Hospice and Palliative Care www.tas.palliativecare.org.au
 Living, Caring, Working www.livingcaringworking.com
 CareSearch online resource www.caresearch.com.au
 National Centre for
 Childhood Grief www.childhoodgrief.org.au

International

American Cancer Society..... www.cancer.org
 Macmillan Cancer Support..... www.macmillan.org.uk
 National Cancer Institute..... www.cancer.gov

Cancer Council library*

Following a cancer diagnosis, many people look for information about new types of treatment, the latest research findings, and stories about how other people have coped. Cancer Council has a range of books, CDs, DVDs and medical journals that may be helpful for you. Call the Helpline for more information.

**Not available in Victoria and Queensland*



Question checklist

You may find this checklist helpful when talking to your doctor about your illness and treatment. If your doctor gives you answers that you don't understand, it is okay to ask for clarification.

- Are there other treatments available that might cure the cancer?
- Will I receive medical treatment if I have palliative care?
- Which health professionals will be a part of my palliative care team and who will coordinate my care?
- Do I have to pay for any palliative care services?
- Where will I receive palliative care?
- If I'm at home, what kind of help will be available?
- Can my family or carer access respite care or other assistance?
- Can I call the palliative care team at any time?
- How long will I need palliative care for? What is my prognosis?
- What will happen in the future to my body? How will I feel?
- I am worried about being unable to support my children financially and emotionally. What help is available?
- Can you help me talk to my family about what is happening to me?
- Are there any complementary therapies that might help?
- Can I get a second opinion about my need for palliative care?

More questions can be found in the 'Resources' section of Palliative Care Australia's website, www.palliativecare.org.au.



Glossary

You may come across new terms when reading this booklet or talking to health professionals. You can also check the meaning of other health-related words on Cancer Council's website, www.cancercouncil.com.au.

advanced cancer

Cancer that has spread deeply into the surrounding tissues or away from the original site (metastasised) and is less likely to be cured.

alternative therapies

Therapies that are used in place of conventional treatment, often in the hope that they will provide a cure.

chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

complementary therapies

Supportive treatments that are used in conjunction with conventional treatment. They improve general health, well-being and quality of life, and help people cope with side effects of cancer.

dietitian

A health professional who helps patients with their diet and nutrition during treatment and recovery.

euthanasia

The act or practice of deliberately ending the life of a person suffering from a terminal illness or incurable condition. It is illegal in Australia.

holistic care

Care that incorporates different types of therapies and services to ensure that your physical, emotional, spiritual and practical needs are met.

hospice

A place that provides comprehensive care for people with a life-limiting illness. This includes inpatient medical care, respite care and end-of-life care for people who are unable to die at home.

life-limiting illness

When an illness is unlikely to be cured and will cause death at some stage in the future. A person with a life-limiting illness may live for weeks, months or even years.

malignant

Cancer. Malignant cells can spread (metastasise) and eventually cause death if they cannot be treated.

metastasis

A cancer that has spread from another part of the body. Also known as secondary cancer.

morphine

A strong and effective pain-killer that is commonly used to treat people with cancer who have pain.

multidisciplinary care

A system where all members of the treatment team collaborate to discuss a cancer patient's physical and emotional needs as well as any other factors affecting their care.

The team meets to review cases and decide on treatments.

palliative care

The holistic care of people who have a life-limiting illness, their families and carers. It aims to improve quality of life by addressing physical, emotional, spiritual, social and practical needs. It is not just for people who are about to die,

although end-of-life care is a part of palliative care.

palliative care nurse

A nurse who specialises in the field of palliative care and is very experienced in helping patients, families and carers with end-of-life care.

palliative care specialist (physician)

A doctor who specialises in the field of palliative medicine, prescribing medical treatment for pain and other symptoms, as well as supporting and advising the other members of the palliative care team, the patient, family and carers.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms of cancer. Treatment may include radiotherapy, chemotherapy or other medication. It is an important part of palliative care.

primary cancer

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body,

where secondary cancers may form.

primary health care

A person's main health care, which is provided by a general practitioner (GP) or a community nurse. It can include initial tests and diagnoses of disease, health promotion, disease prevention, and management of chronic illnesses.

primary health care provider

A health professional, such as a general practitioner or community nurse, who provides the first point of contact for a person to help them with a range of health care matters.

prognosis

The likely outcome of a person's disease.

quality of life

Your comfort and satisfaction, based on how well your physical, emotional, spiritual, sexual, social and financial needs are met within the limitations of your illness.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells

or injure them so they cannot grow and multiply.

relapse

The return of a disease after a period of improvement.

respite care

Alternative care arrangements that allow the carer and person with cancer a short break from their usual care arrangements.

secondary cancer

A tumour that has spread from the original site to another part of the body. Also called a metastasis.

specialist palliative care team

A multidisciplinary team with many health professionals who offer a range of services to improve your quality of life and help with any problems you have. A community nurse or palliative care nurse usually coordinates the team.

terminal illness

An illness that is unlikely to be cured and will result in the person's death some time in the future. It may also be called a life-limiting illness.



How you can help

At Cancer Council we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events like Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

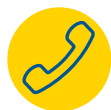
Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contributes financially to our work.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and the impacts of different cancers. You may be able to join a study.

To find out more about how you or your family and friends can help, please call your local Cancer Council.



Cancer Council Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk about any concerns confidentially with oncology health professionals. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

Regional offices

Central and Southern Sydney

Woolloomooloo
Ph: (02) 9334 1900

Central Coast

Erina
Ph: (02) 4336 4500

Far North Coast

Alstonville
Ph: (02) 6627 0300

Hunter

Broadmeadow
Ph: (02) 4923 0700

Mid North Coast

Coffs Harbour
Ph: (02) 6659 8400

North West

Tamworth
Ph: (02) 6763 0900

Northern Sydney

Crows Nest
Ph: (02) 9334 1600

South West

Wagga Wagga
Ph: (02) 6937 2600

Southern

North Wollongong
Ph: (02) 4223 0200

Western

Orange
Ph: (02) 6392 0800

Western Sydney

Parramatta
Ph: (02) 9354 2000

Produced in collaboration with:



Palliative Care NSW



Cancer Council
Helpline

13 11 20

For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: www.cancercouncil.com.au